



# Focus on IBC

August 2008

## IBC Research Foundation Newsletter

### *Inflammatory Breast Cancer Research Foundation Celebrates 9th Birthday!*

In August 1999 my husband and I had the good fortune to share lunch with Owen Johnson, founder and President of the Inflammatory Breast Cancer Research Foundation, meeting to talk for the first time face to face.

At that time the Inflammatory Breast Cancer Research Foundation was coming into its own as an official non-profit entity. This came about after many months of on-line discussions by a group of people who wanted to both raise awareness of inflammatory breast cancer and facilitate research to improve diagnosis and treatment.

### AACR Annual Meeting 2008

In mid-April, I attended the Annual Meeting of the American Association for Cancer Research (AACR) in San Diego. I was fortunate to be accepted for participation in the AACR's Scientist <-> Survivor Program [SSP](#). See the link to the SSP page, to learn about the program; Ginny Mason has attended each of the prior two years, and she is in the banner picture on the SSP page!

Although I've attended many of the AACR Annual Meetings and many of their Special Meetings in the last ten years, being invited to participate as an advocate with scientists was a special privilege.

Gwen Darien and her staff at AACR provided an enriching program of special presentations by leading U.S. and International scientists, especially for SSP participants.

Meeting other advocates and cancer survivors was rewarding, and each participant posted and orally presented a poster about their organization to others. The poster room was open to all whom attended the AACR Annual Meeting.

The program catalog for the many meetings, presentations, and posters for the AACR Annual Meeting is very large; and it is always a daunting task to configure your own personal "program," but the mentors and scientists of the SSP were always available and helpful to point out the "must attend or see" things on the next day's schedule, and to discuss presentations I attended.

I always learn a lot at an AACR meeting, but with the additional reward of participating in the Scientist <-> Survivor Program; this meeting surpassed all

During lunch Owen shared the mission, goals, and vision for this new organization; and immediately I knew I wanted to be a part of this exciting venture! As a survivor of inflammatory breast cancer, diagnosed in 1994, I had been searching for a way to focus my breast cancer patient advocacy work specifically on inflammatory breast cancer, as well as incorporate my medical background as a nurse. I was invited to join the Inflammatory Breast Cancer Research Foundation volunteers and immediately began responding to phone inquiries.

Fast forward to August 2008. The Inflammatory Breast Cancer Research Foundation has come a long way from those early days. The website was developed and recently revamped. Email discussion lists were started. An e-newsletter was launched, and thousands of phone calls and web messages have received personal attention by our Response Team.

Researchers told us they needed easier access to IBC patient tissue samples and

expectations.

*Owen Johnson  
Founder and President  
Inflammatory Breast Cancer Research Foundation*

### ***IBC Survivors Meet in North Carolina***



If you ever get a chance to go to any of the regional IBC get-togethers, I strongly recommend that you make it a priority. In North Carolina, we are pretty spread out, but this is the third year we have gotten together for lunch in the middle of the state. Charlotte Bryant, who did the organizing, also brought a sample of the aprons she has been making that hold drains. She gives them out to mastectomy patients in Greenville. Bonnie Gray brought some new IBC Research Foundation brochures and bookmarks. She filled us in on new research about IBC and things she learned at the American Society of Clinical Oncology (ASCO) meeting. It appears that IBC is now a distinct diagnosis from regular breast cancer, which should help in diagnosis and education about the disease.

Everyone there this year had been there last year too, so it was good to hear how everyone is doing in terms of treatment and follow-up care. Most importantly, we felt a little less alone getting to meet other people who share a history of IBC and know what it is like to fight this disease.

*Phyllis Johnson  
Diagnosed April 1998*

We had a wonderful time in North Carolina on June 21st. It was just too short! We had reserved the room for two hours, but of course that time flew by. Next year we will set aside more time and try to find a restaurant that is more convenient to most everyone. There were five IBC survivors and three family members able to come this year. It was good to see people from last year and catch-up.

Phyllis Johnson, ten years out now, is our role model! Each person shared a little about how they are doing.

associated medical record, if research of inflammatory breast cancer was to move forward. In 2005 the Inflammatory Breast Cancer Research Foundation BioBank and Clinical Data Base began patient enrollment to meet this need. To date, over 140 patients have enrolled and banked their archival tissue (mastectomy and biopsy tissue left over after pathology study) and provided medical records that provide "the rest of the story" to those tissues. Having the clinical history makes the tissue samples much more valuable for research. All materials are de-identified to protect confidentiality.

The Inflammatory Breast Cancer Research Foundation urged the National Comprehensive Cancer Network ([www.nccn.org](http://www.nccn.org)) to update their breast cancer treatment guidelines to identify IBC as a separate and distinct entity from locally advanced breast cancer (LABC.) It took many discussions, as well as providing evidence of the need; but the new IBC treatment guideline was added to the 2008 NCCN Breast Treatment Guidelines!

Bonnie Gray finished her clinical trial and is doing great. Cathy Fallon was scheduled to have reconstruction surgery in July. It is good to get together and be with others who know about IBC and share similar experiences.

*Charlotte Bryant  
Diagnosed May 2001*

## 2008 Era of Hope



*(Edited from Press Release)*

On June 25-28, 2008 at the Baltimore Convention Center, more than 1,500 researchers, clinicians, breast cancer survivors, and advocates gathered at the 5th Era of Hope meeting, sponsored by the Department of Defense (DoD)



Breast Cancer Research Program (BCRP). The Era of Hope meeting is a unique forum for scientists, clinicians, breast cancer survivors (called consumer advocates within the BCRP), and the public to come together and discuss the latest findings in breast cancer research and future directions to eradicate this disease.

The 2008 Era of Hope meeting featured more than 1,200 abstracts focusing on the BCRP's breakthroughs in the prevention, detection, diagnosis, and treatment of breast cancer. The most current topics in the breast cancer community were discussed at the meeting, including disease recurrence, metastasis, stem cells, novel therapies, improved imaging, vaccines, and health disparities.

Ginny Mason, Inflammatory Breast Cancer Research Foundation Executive Director, was one of over 200 consumer advocates attending this meeting. She was invited to attend the Era of Hope meeting as a result of her prior participation as a consumer reviewer of research proposals submitted to the DoD Breast Cancer Research Program. Attendees had an opportunity to learn about the most recent gains in breast cancer research and can now share this information with her community. Some examples of the research reported at the meeting include:

Distinguishing IBC as a unique disease entity will raise awareness, promote research, and impact the design of clinical trials.

Through participation at conferences and other events, the Inflammatory Breast Cancer Research Foundation has established itself in the broader cancer community. We've been involved in clinical trial development and recruitment, research grant review, drug development, and a host of other projects. More exciting things are "in the works" so stay tuned!

Of course, none of this could have happened without the tireless dedication of our Board of Directors and Officers, Medical Advisory Board, and the vast network of volunteers who make up the Inflammatory Breast Cancer Research Foundation. Our gratitude goes out to each of those volunteers, as well as our generous supporters.

It is great to look back over the accomplishments of the last nine years, but we want to set our sights on the future; a future that includes

1. Increasing the accuracy and sensitivity of diagnosis by using molecular breast imaging (MBI).
2. Developing a prophylactic vaccine for breast cancer.
3. Preclinical and early-phase clinical testing of WX-671, an orally administered serine protease inhibitor that appears to inhibit tumor invasion and metastasis.
4. Inhibiting breast cancer stem cells with a self-assembled trastuzumab-nanovector-microRNA as a novel treatment for erbB2-positive breast cancer.
5. Clinical testing of a vaccine containing HER2 intercellular domain peptide in combination with trastuzumab.
6. Examining the biological, toxicity-related, behavioral, communication, economic, psychosocial, cultural, and molecular genetic factors that may contribute to the health disparity seen in breast cancer by creating barriers that lead to less than optimal chemotherapy and hormonal therapy.

Commenting on her experience, Ms. Mason remarked, "At this year's meeting I was given the opportunity to co-chair a special session on inflammatory breast cancer. This was the first time a special session has been devoted to this topic. It was exciting to be a part of sharing cutting-edge research that will improve understanding of this deadly form of breast cancer". The session was well attended by both researchers and advocates. Ken Van Golen, University of Delaware, presented his work AKT1, not AKT2 is involved in RHOC GTPase-mediated invasion of inflammatory breast cancer cells. Paul Levine, George Washington University, reported on E-cadherin levels predict outcome in inflammatory breast cancer. Michaela Hoffmeyer, University of Texas at Austin, focused on Investigation of inflammatory breast cancer biology and potential therapeutic approaches. In addition, Robert Schneider, New York University School of Medicine, shared his work on Inflammatory breast cancer pathogenesis mediated by translation initiation factor eIF4G overexpression and unorthodox protein synthesis.

A number of other inflammatory breast cancer survivors were also in attendance at the meeting. Virginia Hetrick, Jerry Worden, Nancy Key and Pat Haugen have all been a part of the DoD BCRP and were invited to attend the conference. Each of these women have the distinction of being long-term survivors diagnosed at least 10 years ago. We enjoyed spending some time sharing stories and laughs during breaks in the meeting.

Since its inception in 1992, the DoD Breast Cancer Research Program has become the second largest source of breast cancer research in the United States and has

breakthroughs in the understanding, diagnosis, and treatment of inflammatory breast cancer.

The Inflammatory Breast Cancer Research Foundation remains, "COMMITTED TO FINDING THE CAUSE/S" and we invite you to join us in this quest.

*Ginny Mason RN, BSN  
Executive Director, ibcRF*

### *Upcoming Events*

**Sept. 2-3** Biomedical Informatics Without Borders Meeting, Bethesda, MD

[Click here.](#)

**Sept. 4**

Cancer Advances: A Public Forum on Breast Cancer, Washington, DC  
RSVP required to attend. [Click here.](#)

**Sept. 5-7** 2008 ASCO Breast Cancer Symposium, Washington, DC

[Click here.](#)

**Sept. 12** National Advisory Council for

received over \$2 billion in congressional appropriations, resulting in more than 5,000 unique awards that fulfill unmet needs in breast cancer research. Unlike other cancer research organizations, the BCRP is a pioneer in the inclusion of consumer advocates in every aspect of the research process. Since the program's inception, almost 600 survivors have participated in the program, including setting the program's vision, participating in the review of proposals, making funding recommendations, and aiding in the research process.

Through this approach of combined involvement, the BCRP enhances partnerships between the survivor community and scientists. The survivor's unique perspective brings a sense of urgency to the program, ensuring the Breast Cancer Research Program remains focused on its ultimate goal of eradicating breast cancer. Captain E. Melissa Kaime, M.D., Director of the Congressionally Directed Medical Research Programs, expressed her appreciation for the consumer advocates' perspective by stating, "They have provided valuable insight into funding decisions and helped the scientists understand the consumers' perspective of innovative research. Likewise, the consumer advocates have been enriched by learning more about breast cancer through discussing proposed research with scientists and seeing the future hopes of successful research. It is exciting for all of us to join perspectives, review these new research findings, and explore our best future paths in breast cancer research."

*More information about the Department of Defense Breast Cancer Research Program is available at <http://cdmrp.army.mil>*

### Lapatinib Limits Growth of Breast Cancer Brain Metastases in Mice

Investigators from NCI's [Laboratory of Molecular Pharmacology](#) report that in a mouse model of breast cancer, the small-molecule inhibitor [lapatinib](#) (Tykerb) can cross the blood-brain barrier and prevent approximately 50 percent of large HER2-positive brain metastases. Their study appeared online July 29 in the [Journal of the National Cancer Institute](#).

The drug [trastuzumab](#) (Herceptin) targets cancer cells that overexpress the protein HER2. These cells have shown a greater potential to spread (metastasize) to the brain, but trastuzumab, a large antibody molecule, cannot cross the

Complementary and  
Alternative Medicine  
Meeting, Rockville, MD

[Click here.](#)

**Sept. 15** FDA: Clinical  
Trials for Local  
Treatment of Breast  
Cancer by Thermal  
Ablation,

Silver Spring, MD

[Click here.](#)

**Oct. 12** Frosted Pink  
with a Twist; ABC  
broadcast from 4-6 pm  
(ET). ASCO sponsored  
event to raise  
awareness of women's  
cancers. [Click here.](#)

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blood-brain barrier to reach these metastatic cells.

Lapatinib, which is approved for the treatment of metastatic breast cancer, is a much smaller molecule that is capable of permeating the blood-brain barrier. Its effectiveness in clinical trials treating large secondary tumors in the brain has been limited, so the researchers wanted to see if it might be better at preventing the growth of these tumors when they are still small.

They injected mice with a breast-cancer cell line engineered to overexpress HER2. The mice received a low or a high dose of lapatinib, or a control solution, twice daily for 24 days. Those that received lapatinib in either dose developed half as many large metastases as those that received the control solution.

"What our model system shows is that lapatinib might prevent micrometastases from growing into life-threatening macrometastases," explained Dr. Patricia Steeg, senior author of the study. In the future, stated the authors, preventative therapy to suppress the growth of micrometastases could possibly be combined with standard treatments for large brain metastases, such as neurosurgery or radiation therapy.

*Source of Article: NCI Cancer Bulletin*

<http://www.cancer.gov/ncicancerbulletin>